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ABSTRACT

Designed for state Developmental Disabilities Planning Councils, the booklet presents seven papers dealing with public awareness of handicapped persons. M. Reilly describes the Connecticut Council's project to make contact with key groups of decision makers. The Vermont project is explained by T. Knox in terms of program goals and public relations activities on a low budget. R. Valela cites the need for society to make significant changes in planning, service delivery, and public awareness to incorporate consumer involvement and advocacy concepts. B. Aiello reviews class activities for regular educators and students to understand the effects of handicapping conditions. J. Panza, Jr. describes his experiences working with policy officers in New Jersey, and D. O'Connell considers the role of institutions. (CL)

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Public Awareness Viewpoints

Gary Richman *Pascal Trohanis*

Editors

A Booklet for State DD Councils
Prepared by DD/TAS

Spring, 1978

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TABLE OF CONTENTS

Chapter 1

An Introduction to Public Awareness Viewpoints: Looking Back and Looking Forward 1

Gary Richman
Pascal Trohanis

Chapter 2

CONN-TACT: A Personal Approach to Decision Makers 5

Maggie Reilly

Chapter 3

Vermont "Project Awareness" 15

Toby Knox

Chapter 4

Self Advocacy and Changing Attitudes 27

Rita A. Varela

Chapter 5

Hey, What's It Like to be Handicapped? Practical Ideas for Regular Class Teachers and Their Students 37

Barbara Aiello

Chapter 6

Awareness Training for Police 47

Joseph A. Panza, Jr.

Chapter 7

Institutions. . . . What Do We Do in the Meantime? 59

Daniel J. O'Connell

Chapter 1

An Introduction to Public Awareness Viewpoints: Looking Back and Looking Forward

Gary Richman
Pascal Trohanis

Developmental Disabilities Councils continue to confront barriers to improving services for persons with disabilities and they continue to discover that these barriers are often a mixture of inadequate or erroneous information and negative attitudes. The experience of the DD movement over the past six years has shown that DD Councils can marshal the energy, resources, imagination, skills and tools to effectively attack ignorance and prejudice.

Ignorance and prejudice will never be permanently vanquished, but they can be neutralized and held in check by continuing, thoughtful, creative efforts. But, even as we may feel a sense of accomplishment in one area, the success of the DD movement as advocates for change has added to our public awareness workscope. Moving people with handicaps from remote institutional settings into the community means that we need to communicate more, and more effectively, with neighbors, local officials and community leaders. Our legislative success in civil rights with Section 503 and 504 means that we must be prepared to communicate with those who run corporations, hospitals,

universities and every sort of health and social service agency. Realizing the benefits of the mandate we have achieved in The Education for All Handicapped Children Act (PL 94-142) will be dependent, in great measure, on our ability to "educate" and persuade administrators, school boards, teachers and students.

It is in this spirit that this book, and all of our technical assistance activities, have been offered. Over the years, DD/TAS has tried in other books, in training conferences and individual consultation, to explore with Councils the role of public awareness, how to plan and implement activities, what resources already exist and what new territory needs to be surveyed. Public Awareness Viewpoints continues that commitment. The chapters in this book offer a variety of viewpoints and perspectives. First, we feel that it is important to reinforce the idea that DD Councils have been effective in public awareness and that they have done so by being creative. Maggie Reilly, the Public Information Officer for the Connecticut Developmental Disabilities Council, writes in Chapter 2 about their latest public awareness project. Dubbed "CONN-TACT," it tackles the difficult problem of making contact with key groups of decision makers.

Toby Knox, currently president of Creative Communications, Inc., was the director of Vermont's "Project Awareness." In Chapter 3, he reviews the variety of strategies they used, each designed to get maximum mileage and to take advantage of the Vermont way of life.

The remaining chapters in this book look at current trends and issues and the implication they have for public awareness activities now and in the future. Perhaps the most fundamental of these issues may be how we resolve the internal conflicts between our philosophy and our actions. In Chapter 4, Rita Varela, Special Projects Manager for the American Coalition of Citizens

with Disabilities in Washington, D.C., discusses the implications of our philosophy of consumer involvement and advocacy. She challenges us, as a society, to make some significant changes in planning, service delivery and public awareness which will incorporate these concepts into our actions.

And what about making the philosophy of mainstreaming in education work? In Chapter 5, Barbara Aiello, a consultant on the handicapped with the Learning Institute of Palo Alto, California, writes about techniques to shape the attitudes of students and teachers alike, toward the handicapped child in the classroom.

As more and more persons with disabilities live in community settings there are increasingly more audiences whose attitudes we would like to shape. One example is police officers. Joseph Panza, Jr., Field Representative for New Jersey protection and advocacy system, Advocacy for the Developmentally Disabled, writes in Chapter 6 about his experiences working with this key audience.

If the trend is toward community residences and away from institutional care, what do institutions do in the meantime? This is the question addressed in Chapter 7 by Dan O'Connell, Superintendent of the Hartford Regional Center in Connecticut.

Finally, we have tried in this book to offer a wide array of strategies and issues which, while we could never cover the entire field of public awareness, give a sense of its breadth. We often have a clear view of just how many problems and barriers are a function of ignorance and prejudice; we hope this book suggests that the tools and resources for dealing with these problems are as vast as our creativity and imagination can make them.

Chapter 2

CONN-TACT: A Personal Approach to Decision Makers

Maggie Reilly

Individuals whose decisions directly affect the lives of developmentally disabled people still often know surprisingly little about handicapping conditions or about services available to those who are handicapped. This was one conclusion reached by members of Connecticut's DD Council as they attempted to assess the impact of an active public awareness effort primarily intended to reach the general public. Through their experiences as consumers and service providers, Council members identified local elected officials, state legislators, and members of the medical community as decision makers who appear to be in need of more information.

Focusing on Decision Makers

The actions and attitudes of local elected officials have important effects on the lives of developmentally disabled citizens of their communities. Housing Assistance Plans should, but sometimes don't, appropriately include handicapped persons. Revenue sharing monies can be spent on services for

citizens with developmental disabilities, but are sometimes returned unspent. Local school districts must provide education for handicapped children, but school and town officials sometimes feel that the state and federal governments are forcing them to meet stringent requirements for children they don't know much about. Zoning boards are approached by service providers wanting to establish community-based residential facilities and are often unduly concerned that the presence of a group of handicapped persons will have a negative impact on the community. And, sometimes, town officials don't really seem to understand that handicapped persons are citizens who live, work, vote, and shop in their communities, and who, like other citizens want and need to make use of municipal services.

The Connecticut legislature meets for a few months every year, and during this short time must make decisions on a wide variety of issues affecting state residents. Service providers and consumers annually find themselves attempting to educate legislators about the capabilities, needs, and rights of handicapped persons at the same time as representatives of seemingly countless other interest groups are trying to inform lawmakers of their special needs. This is often confusing to the legislators and results in the passage of some laws that are not very responsive to the needs of developmentally disabled persons.

A recent survey made by the Department of Mental Retardation showed that pediatricians are sometimes very late in identifying children as developmentally disabled and in referring them to the infant stimulation and early intervention programs that they need. Also, parents are still sometimes advised to place handicapped children in institutions without being informed of alternatives, the community-based services that are available to them. Pediatricians and other members of the medical community serving infants and children are

often seemingly unaware of programs and services for their patients who are developmentally disabled.

The Emergence of CONN-TACT

Council members agreed that developmentally disabled persons would have an improved chance of fully developing their capabilities and participating in community life if they were better understood by local and state officials and by members of the medical community. It was recognized, however, that elected officials and doctors are busy people who receive a lot of mail and a lot of visits from people who are asking for services or demanding changes. To reach them effectively, it seemed important to visit them personally since mail so easily piles up unread. In addition, it seemed important that the visits be friendly and informative conversations initiated by concerned and aware but undemanding persons. As a result of this thinking, preliminary plans were made for the formation of a network of individuals who would personally deliver relevant, readable, and attractive materials. This personal approach to decision makers was to become known as Project CONN-TACT.

Once the three target audiences had been identified and the strategy of reaching them on a face-to-face basis selected, Council members had to determine which group of decision makers should be approached first, who should make the visits, and when the visits should be made.

There were several reasons for deciding to approach chief local elected officials in the first year of the project. CONN-TACT would begin in an election year for mayors and first selectmen, and, it was believed that newly elected officials would be especially receptive to background information designed to help them respond to some of their constituents more effectively. Also, the enactment of P.L. 94-142, the promulgation of regulations for Sections

503 and 504 of the Rehabilitation Act of 1973, and the establishment of new Committees on the Handicapped in many local town governments could be expected to influence the relationships of town officials with their developmentally disabled citizens in the years immediately following initiation of the project. Since Connecticut has no county government structure, the actions and attitudes of local elected officials are especially important to handicapped residents of the state.

Implementing CONN-TACT

The question of who should make the visits was a cause for some concern, especially after a Council member who had served in the state legislature advised that elected officials were most responsive to information presented by their own constituents. Locating a volunteer from each of Connecticut's 169 towns appeared to present an almost insurmountable challenge. Fortunately, however, through Project SHARE, the Federation of Women's Clubs is committed, on a national level, to increasing community awareness of persons with developmental disabilities, and members of the Connecticut organization had approached the Council to ask how they might be involved. When preliminary plans for CONN-TACT were presented to them, their response was overwhelmingly enthusiastic. The Women's Club representatives suggested that they would be able to locate a regional coordinator for each of their eight districts within the state, and, that through these regional coordinators, a representative from nearly every town could be identified.

Together, the Women's Club representatives and Council members agreed that mayors and first selectmen should be visited as soon as possible after assuming or resuming office following the November elections. Since this meant that in most Connecticut towns visits would be made in November, December, and January,

a volunteer orientation session was scheduled for late October. While the Women's Clubs' representatives spent the late spring and summer months identifying regional coordinators and local CONN-TACT volunteers, Council members and staff enlisted the aid of the Developmental Disabilities/Technical Assistance System (DD/TAS) to plan for the development of appropriate materials for local elected officials and training for volunteers.

The planning group agreed that mayors and first selectmen would be more responsive decision makers if supplied with information about the developmental disabilities, about available services, and about successful town-sponsored programs that might be duplicated in other communities. Local elected officials, it was agreed, would also benefit from a reminder that developmentally disabled persons are citizens who often vote, pay taxes, and utilize services of the towns.

In order to communicate this information, the following materials were obtained or developed for dissemination:

"What are Developmental Disabilities?" - a brochure produced by DHEW which offers an overview of the federal Developmental Disabilities Program and briefly discusses each of the four disabilities.

"A Handy Reference to Developmental Disabilities Jargon and Acronyms" - defines the terms and acronyms used to describe handicapping conditions, services, and key pieces of legislation. (This brochure is a Connecticut version of "Handicapped-ese," produced by the Oregon DD Council.)

"Connecticut Organizations Serving Persons with Developmental Disabilities" - brief descriptions of state-sponsored programs and statewide voluntary association, with addresses and telephone numbers.

"Questions and Answers about the Developmental Disabilities" - questions Council members have heard often, especially those about developmentally disabled citizens' participation in community life.

"Local Governments in Action for Citizens with Developmental Disabilities" - brief descriptions of programs in three towns, with addresses and telephone numbers.

A mini-phone directory with addresses and phone numbers of key public and private service providers. Local information was handwritten by the CONN-TACT representative from each town.

A post card to be returned to the developmental disabilities office by town officials wanting more information.

Since mayors and first selectmen usually keep information in file cabinets, the CONN-TACT materials were delivered in bright green or yellow file folders with "Developmental Disabilities" printed on the tab. Town officials should easily find a place for the information, and the brightly-colored folders are sure to be noticed each time the drawers are opened. The mini-phone directory was designed to slip neatly under a desk phone so that it would always be handy.

Training CONN-TACT Volunteers

CONN-TACT volunteers, it was agreed, need not be experts, but should know enough about the disabilities and service organizations to make a brief presentation to their local officials. They should be comfortable in approaching their mayors or first selectmen and should be prepared to respond to general questions.

Orientation was provided through a written tool kit and at a day-long orientation session. The tool kit contains an overview of CONN-TACT, the descriptions of the disabilities prepared by the Developmental Disabilities/Technical Assistance System for their Orientation Notebook, and outlines of the roles of the local volunteers and regional coordinators. At the training session, volunteers learned about current trends in services to persons with developmental disabilities and were provided with background information on each of the four handicapping conditions. They heard representatives of the statewide voluntary associations describe their programs and listened to first selectmen from two Connecticut communities discuss how and when they might

best be approached. Through watching I'm Not What You See, the Canadian Broadcasting Corporation's film of a television interview with Sondra Diamond, the volunteers had an opportunity to acquire a new awareness of what life is like in our society for a person who is handicapped. Finally, in small group meetings with their regional coordinators, the CONN-TACT representatives learned how to complete the mini-phone directories with local numbers and how to report on their visits. Feedback forms returned by the volunteers at the end of the day indicated that the training was successful in that nearly everyone felt that she understood her role as a CONN-TACT representative, that she had been supplied with adequate information about the disabilities and available services, and that she would be comfortable in approaching her mayor or first selectman.

What's Been the Impact of CONN-TACT?

As of this writing, most of the visits have been made and written reports describing about one-half of the visits have been sent to the developmental disabilities office. Although more will be learned from the remaining written reports and at a planned follow-up meeting with the regional coordinators, there is some information to share at this time.

Nearly all the CONN-TACT representatives who completed written reports noted that they were very well received, and many said that their mayors or first selectmen were aware that they needed the type of information presented and would find it useful. The volunteers had extra file folders and were instructed to ask whether the information would also be appropriate for other town officials. In most towns, additional file folders have been requested for and distributed to representatives of the school system, the Health Department or Visiting Nurses Association, and the Social Services Department.

Many volunteers have personally met with these and other interested persons in town governments.

CONN-TACT representatives residing in each of Connecticut's 169 towns were not located, and consequently, some local officials were visited by Women's Club members residing in other communities. Although well received, these volunteers felt that visits from constituents would have been more effective.

A key factor in the apparent success of Project CONN-TACT has been the enthusiastic and competent leadership provided by the regional coordinators and the Community Education Chairman of the Connecticut State Federation of Women's Clubs. These women have encouraged volunteers to participate, kept track of their activities, and reminded them to follow through with their commitments. As a result of their efforts, members of Women's Clubs throughout the state have become aware of CONN-TACT, and also of their developmentally disabled neighbors.

Council members are presently making plans to continue Project CONN-TACT for at least two more years in order to reach legislators and members of the medical community. Legislators will be approached next since elections for state officials are scheduled for the coming November. Members of the medical community will be the target audience in the third year of CONN-TACT when efforts will be made to reach clinics, school nurses, and others providing medical services to children in poverty areas as well as pediatricians in private practice.

It is too early to decide whether CONN-TACT will continue beyond the presently planned three year period. However, Council members have begun to think of ways to keep the already identified audiences informed as services

and legislation change. Also, additional groups of people who impact on the lives of developmentally disabled persons are being identified, and consideration is being given to approaching some of these groups through personal, face-to-face visits, with specifically designed materials.

Chapter 3

Vermont "Project Awareness"

Toby Knox

Writing an article on the DD Council's citizens awareness activities in Vermont requires the same approach as does the planning of a citizens awareness program. A most important series of decisions must be made before pencil is put to paper or the first brochure is designed or PSA is written. Someone or some policy making group must answer the questions: What is it we want to say, to whom and why? In other words, goals must be established and strategies to achieve those goals must be determined.

From the start, let's define a few terms which will be used in this article and should be a part of any citizens awareness effort.

A goal is a desired result. In the case of a citizens awareness program it may be a goal with a broad scope, such as increased public acceptance of persons with developmental disabilities, or a goal with a narrow scope, such as an informational campaign on the housing needs of the handicapped directed to a zoning board or a housing authority.

A strategy is the overall game plan devised to achieve the goal. There may be many ways to communicate a particular message. The reasons to select one approach or technique as opposed to another, or two approaches in tandem, must be based on an overall plan or strategy.

Often communicators confuse strategy and techniques, the methods or media used to present the message or information. We all like to see the finished product and are proud to present it to the Council as we did in school "show and tell." If the medium, however, will not achieve or help to reach the goal, it should not be chosen.

The difficult part of this process comes before the brochure is written, the newsletter printed or the slides photographed.

The questions which must be asked before any project is set in motion are: why are we doing it; will it help achieve our goal; how does it fit into the strategy. You will save yourself time, effort and money if you answer those questions as the first step of any citizens awareness project.

Establishing Goals

The Vermont Developmental Disabilities Council established its "Project Awareness" in January of 1975. The need for the project stemmed from a Council perception that the general public and certain specific groups did not understand the needs, hopes and desires of the developmentally disabled population.

In September of 1974, the Council developed a list of ten barriers to service. Of the ten barriers, three of them dealt in some way with the lack of citizens awareness. The barriers were described as follows:

1. "Consumers and professionals lack information regarding the existence of appropriate services and means of access to them."

2. "Lack of knowledge about developmental disabilities and community responsibility for developmental disabilities."

3. "Public fear and ignorance about developmentally disabled people."

These barriers have served as a guide and overall goals throughout the Project's existence.

Vermont

Vermont is a small state with a population of under half a million. There are approximately twenty thousand persons with one or more disability. As is the case in many states, the focus is starting to turn towards community living and more or better community based service delivery systems. The ten community mental health agencies which cover the states fourteen counties are developing into combined community mental health - developmental disabilities agencies and the four private citizens' advocacy groups are increasingly active throughout the state.

The DD Council receives the minimal federal allocation and thus does not have a large amount of money for the many areas requiring attention. While citizens awareness has been a high priority for the last three years, the budgets of Project Awareness have been modest, never reaching above twenty-seven thousand dollars for a fiscal year. However, that the budget was never less than eighteen thousand dollars reflects the Council's substantial commitment to citizen awareness.

Doing a Lot with a Little

Following sound advertising and communications practices, one of the first strategies adopted was the decision to tie as many pieces of the Project together as possible. In other words, to achieve the maximum impact for a small

number of dollars spent we knew we would have to reinforce our message by coordinating the way we selected and utilized various communications techniques.

The second decision, mostly dictated by budget, was to undertake programs which would be inexpensive and yet directly or indirectly reach the audience(s) desired.

A third important aspect of the strategizing was the resolve to take advantage of communications opportunities which were an intrinsic part of the Vermont lifestyle.

Toll Free Telephone

One of the first, and most successful, programs initiated was a toll free telephone line for consumers and others in search of assistance or information. The line, dubbed Dial Direct 4→ Developmental Disabilities or the "4D" line, is answered by the staff of the Community Mental Retardation Services Division of the Department of Mental Health. The purpose of the service is to provide information regarding the existence of appropriate services and to provide assistance in achieving access to them.

Numerous techniques were utilized to announce the line's existence and publicize the number. In addition to radio and television public service announcements and general press releases, a number of methods were tried which had small price tags and extensive visibility.

Following in the tradition of Alexander Graham Bell, the Council invited Vermont's Governor to answer a pre-arranged first call from a Council member, calling from the other end of the state, to officially open the line. A short dedication ceremony was held to which all consumer groups, community mental health agencies, state government service delivery agencies, members of the Legislature, Vermont's Congressional delegation and the press were invited.

Favorable and widespread media coverage was given to the inauguration of the "4D" line.

A discussion was held among members of the Council's Citizens Awareness Committee, the Project's review board, as to how to inform the group of Vermonters who might not read the newspapers or watch much television or listen to the radio about the existence of the line. Two methods were selected.

The first entailed having a poster designed and printed. The poster and a covering letter were sent to all of Vermont's town or city clerks with a special request. The first Tuesday in March is the traditional day Vermonters in all of the state's two hundred and forty-six organized town and cities meet at the town or city hall to hold local elections, set town and school budgets and policy, and discuss town problems. It also is usually the only day in the year that townspeople get together in one location.

The request to the town clerks was to place the "4D" line poster in a prominent location at the town hall. A telephone follow-up survey of town clerks after town meetings showed that many complied with the request.

The second publicity technique generated the broadest exposure to the line's number. Pitney Bowes' postage meter plates were made for the State government's six postal outlets. Every piece of mail metered by the State of Vermont for over six months advertised the Dial Direct line. This means that every licensed motorist, every person receiving a tax form, every person on welfare and unemployment assistance or anyone getting anything from the State received an envelope with the toll free line number imprinted on it.

A third way utilized to inform potential users of the line of its existence was to have the poster reduced to a size that would fit into a business size envelope. These mini-posters, printed on a card stock, were stuffed in mailings and distributed to locations where they might be picked up, such as

community mental health centers, state advocacy offices, state teachers convention and so on. One of the state's largest banks placed one in each bank statement. Unfortunately, a similar request made to the New England Telephone Company for stuffing a card in each bill was turned down.

Press Kit

No one disputes the power of the press as "gatekeepers" of information reaching the general public. It seems, however, that few people take the time to educate the press or give them the appropriate background information which is required for understanding an event or writing a story.

As the term developmental disabilities was new to almost everyone and few seemed to know much about the disabilities, a press kit was organized and distributed to all press statewide. The contents consisted of some materials already in existence and some especially prepared.

The information pieces were as follows:

* Individual pamphlets on each disability written in lay terms, including specific sources for further information as well as the 4D line number.
* A similar pamphlet on developmental disabilities, the Council and its mandate.
* A roster of Council members including address and telephone if the local press desired a local contact.
* Information on the 4D line.
* A profile of Council activities and Council grants.

A cover memo from the Council Chairperson explained the reason for the kit and invited requests for additional materials. While it was not anticipated that every kit would be read from cover to cover the materials were assembled in a specially designed file folder for future study or reference.

Talk Shows

Numerous opportunities exist for free time on radio and television. Being a small state, however, Vermont has very few stations. However, being small makes it feasible to drive to any part of Vermont within several hours and hitting all twenty radio stations with an interview or talk show, therefore, is not impossible. These shows have a high level of credibility with their audience and command faithful and loyal listeners.

Television interview shows in Vermont are not as plentiful as on radio. There are three television stations in-state and several which cover Vermont from neighboring states. On several occasions the Council Chairperson or the Commissioner of Mental Health appeared on television and discussed developmental disabilities. In keeping with our decision to tie all the pieces of the citizens awareness program together, on each radio and television show the "4D" line was plugged and the informational pamphlets were offered to the audience.

Targeting the Message

While a large portion of the Project Awareness program was directed to the general public with hopes it also would be of consequence to certain subgroups, specific messages were targeted to selected audiences. Narrowing the scope of the information to be transmitted to meet the interests of a group often can be the most fruitful part of an information and education project.

Too often the challenge offered to a citizens awareness program is to educate the public and change attitudes. While this is not an impossible task, it is a time consuming, expensive and, perhaps, a frustrating experience. Transmitting small amounts of information to a certain public within the general public, however, can prove to be a worthwhile and rewarding endeavor.

Legislators Fact and Information File

The Vermont Council identified the members of the Vermont Legislature as being an audience which needed accurate and factual information on the subject of developmental disabilities. As with members of the press, state legislators are presumed to be experts on all subjects. Without staff and with limited research facilities available, legislators cannot hope to be aware of all the problems facing the state's residents and the government.

In an effort to assist legislators become familiar with the needs, hopes and desires of individuals with a disability and the problems they face, Project Awareness designed and assembled an introductory fact and information file. In keeping with the principle of making a little go a long way, many of the materials of the press kit were also designed with the legislators in mind. The materials were sent to members of the General Assembly at their home address before the legislative session commenced. A personally typed cover letter from the Council Chairperson invited requests for additional or more specific information.

A postcard survey of legislators taken by the Council at a later date showed that a majority of lawmakers appreciated the information and found it helpful.

The Council also has sponsored an annual luncheon for legislators during the legislative session to review the Council's legislative platform and give Council members and representatives and senators a chance to discuss mutual concerns. Building on these two foundation blocks, Project Awarenss had a seminar for Council members to make them more effective in "influencing" legislation. The purpose was to educate Council members as to the "ins" and "outs" of the legislative process and while some of the information was old hat to more experienced Council members, the general consensus seemed to be that the

time was well spent.

Technical Assistance

Several unsuccessful attempts by local organizations to open group homes in communities led the Council to take a long look at future state plans to develop intermediate care facilities for the developmentally disabled. As has been the case elsewhere, in several communities neighboring residents, homeowners and the town zoning commissions reacted negatively to a proposal to establish a home for developmentally disabled adults.

In an attempt to avoid such reactions, confrontations and negative public debate, the Project offered technical citizens awareness assistance to the state's community mental health agencies who were planning to site, place and operate ICF/DDs. The program was divided into five phases. The first phase called for a study of successful and unsuccessful community-based residence siting and placement efforts and to determine what the plans and needs of community mental health agencies were. Phase two called for the preparation of a model citizens awareness strategy and plan. Phases three and four were to review the model strategy with groups planning the development of housing and adapt the strategy and plan to local needs. The last phase was to serve as a technical consultant to groups with needs in the citizens awareness area.

Due to difficulties at other levels in obtaining the funds and contracts, the development of ICF/DDs did not occur as planned. The one community mental health agency which started the process and received assistance from Project Awareness later voted not to have an ICF/DD and ceased its efforts.

The idea, however, of providing citizens awareness assistance or consultation to organizations such as community mental health agencies is a valid one. We are all aware of unhappy and unfortunate situations which may occur

when group homes are suggested for a neighborhood. Often this is the case when the persons sponsoring the home do not plan ahead and take sound public relations steps to offset, negate or minimize any opposition. This is an example of where targeting a message to a specific group or groups really can pay off.

The examples given here are a few of the activities undertaken by the Vermont Developmental Disabilities Council's Project Awareness during a three year period. If anything has been learned throughout this period it is that the campaign for the hearts and minds of our audience(s) is a never ending one. With consumers being deluged with 1,800 to 2,500 advertising messages a day, the competition for being remembered is stiff. With General Motors, Coca-Cola and General Foods spending millions of dollars a year to sell their products or to keep them in front of the consuming public, a few public service announcements, brochures, newsletters, and slide tapes seem like a lean arsenal with which to offset ignorance, abate fear and help to persuade the public that persons with disabilities have needs, hopes and desires similar to all citizens.

It may sound like an insurmountable task, but it can be done. Changing or formulating public opinions and attitudes demand commitment and patience. A constant vigil should be kept for positive citizens awareness opportunities, and the attention of the public must not be allowed to shift when issues demand action.

John Wanamaker, the Philadelphia department store executive, has been quoted as saying he never knew which half of his advertising budget was being spent in a beneficial manner and which half was being wasted. He did know, however, that he could not stop advertising.

Developmental Disabilities Councils cannot always put their fingers on the rate of attitude change or opinion formulation toward their state's disabled population. When it comes to budget preparation time, the lack of a clear

evaluation can often be frustrating and could possible mean the shifting of dollars and commitment to other projects.

DO NOT LET THIS HAPPEN! DD Councils must continue to support citizens awareness projects and keep the concerns and goals of individuals with disabilities before the public. Citizens awareness is another term for communications, and only by communicating openly, often and effectively will the needs of persons with developmental disabilities be heard.

Chapter 4

Self Advocacy and Changing Attitudes

Rita A. Varela

What are society's attitudes towards the disabled person? How can those of us who are concerned with public awareness change them? Are they changing already, without our help or control, as a result of the disabled self-advocacy movement? We cannot even begin to tackle these questions until we examine the relationship between disabled people and the rehabilitation service delivery system.

Special Processing

Disabled citizens are probably the most counselled people in America. They are, indeed, a managed community. Though our society prides itself on its willingness to help the handicapped, the mechanisms it has created to dispense its benevolence have -- at times subtley and at times, as in the case of certain custodial care institutions,[1] brutally -- worked to surpress assertiveness and self determination. Some disabled citizens do slip into the mainstream without help. Most, however, find that in order to get into the educational system, the health care system, and the income systems (jobs or government income ma ntenance) they must submit to special processing. From the time their difference is first diagnosed and noted they become legitimate

targets for counseling and advice. They are constantly exposed to the same, negative message: "You've got to be fixed up." And in the course of the processing they become exiled, sometimes permanently, into a world of special doctors, special teachers, and special counselors who have been assigned to do the fixing. This processing has a profound impact both on the self concept of disabled people and on society's view of them.

For the disabled person, processing means being set apart: bouncing in, out, and through countless programs, evaluations, agencies, and clinics; only to return, each time, to a sundered path, adjacent to society yet never with it; forever gazing towards the city from the woods; and confined, condemned like Sisyphus, to a road that veers from life. What gives this a political dimension is that it is not on a road at all but on a bureaucratic conveyor belt. The route is predestined by bias and by a network of laws and agencies which rule that if you are born or become disabled you automatically fall under an alternate set of procedures. The network is manmade and alterable. Disabled kids have not been put in special classes to satisfy the laws of physics but, rather, the laws of the state. Parents, furthermore, can have a lot of influence on the legislature when they get fed up and start organizing.

Still, the very magnitude of the processing system is oppressive. Without realizing it, disabled persons do, at least in part, begin to accept the assumption that there is something wrong with them and that human service personnel have a right to intervene. Yet chances are that the consumer has gone to a great many fixers through the years and still has big problems: no job, no transportation, no accessible housing. Some the the counselors may have even proposed conflicting remedies. What we have, then, is a client who has received too much feedback to trust himself and not enough positive rewards to trust the specialists.

The Selling of the Disabled

For society, the special processing means that somebody -- somebody else -- is handling disabled people and that there is no need for the average, non-disabled citizen to deal with them or be concerned about what's going on. Many people hear about disability issues primarily through telethons and public service announcements, and consumers have not always been pleased at the way these vehicles portray them. Too often, telethons have sought to merchandize the disabled child, who is generally depicted as cute, helpless, and somewhat pathetic. Sometimes telethons have also tried to sell the horror of disability, and the audience has had to watch as the celebrity host wipes a tear from his eye and tells them that if their children are normal they should thank God every day.[2]

Public service announcements are far less maudlin, and do, undoubtedly, convey important information. Disabled persons and their families should know about community referral services and rehabilitation centers. Yet the PSAs also tend to reinforce the traditional perspective by telling the public that (a) there is something special out there which has been set aside to handle those people, and (b) if you support such ventures -- either by giving money to a charity or by giving passive approval to a government sponsored program -- you're off the hook. The pity, the helplessness, and the horror of disability, when presented in conjunction with scenes of bright, shiny, photogenic offices filled with up-to-date equipment to deliver top-notch services, work to justify the special processing and exile. It is neither the telethons nor the PSAs themselves that are deplorable, but rather the absence of a second and more objective correlative between the lives of disabled people and the stuff we are told about this population.

Where is Judy Heumann, who started Disabled in Action, who led civil rights demonstrations, and who was carried off an airplane and arrested simply because she uses a wheelchair? Where is Frank Bowe, director of the American Coalition of Citizens with Disabilities, who works sixty and seventy hours a week to ensure that the voices of disabled Americans are heard in Washington, D.C.? And where are the millions of others, who remain unknown but who work and pay taxes, who struggle and dream, who have babies, who get divorced, who die without finishing their novel? No, we aren't told about them. Telethons and PSAs are carefully designed to perform very specific functions, which, ultimately, are supposed to make it easier for disabled individuals to get along in society. Unfortunately, the picture they draw is rather alien and sterile, and often confirms the suspicion that people like that are not kin to a world like this.

Self-Advocacy and Changing Attitudes

The disabled self-advocacy movement represents a growing challenge to these bleak and sterile portraits. True, the movement does not speak with a single voice.[3] It is a large, loud proliferation of leaders from different sized groups, some cohesive and some not, that, at first glance, seem to share only their commitment to those whom society has left behind. On closer examination, however, one finds three major themes of consensus.

The first theme is that the fixers aren't fixing much, and that there is a need for new strategies. The human service system, generally, has viewed the problems of education, housing, jobs, and transportation as stemming from the deficits of the client. The client, therefore, had to be altered; made adaptable to the environment. The movement, however, has seen them as problems of access, of a system that is not distributing benefits equitably, and

has often sought redress through legislation and the court.

A second theme concerns the attitudes of human service personnel towards disabled persons. Consumers charge that counselors see only the client's disability, not the potential, and that counselors always show a livelier interest in behavior modification than in affirmative action. There is a disturbing amount of evidence indicating that these charges may have some merit. Harold E. Yuker and the staff of the Human Resources Center in their historic and comprehensive study, found that the attitudes of a rehabilitation worker towards clients tends to become increasingly negative as the years pass.[4] The study also found that the attitudes of rehabilitation professionals towards the disabled tend to be more negative than do the attitudes of employers, non-disabled co-workers, or non-disabled school peers.

Do these attitudes affect the quality of rehabilitative planning? Some innovators within the profession feel the answer is yes:

> The vocational rehabilitation of persons with severe disabilities has a long history, a history of failure. It is a history dominated by an expectancy cycle that perpetuates low levels of success and low employment capabilities.
>
> Virtually all that has been attempted has taken place in the context of simple, menial tasks that require little training, skill or attention. In fact, most program descriptions that are available focus on tasks that are labor intensive rather than machine intensive, thereby accentuating the disabilities rather than the capabilities.[5]

A third and closely related theme concerns self-help. The programs sponsored by Berkeley's Center for Independent Living and Minnesota's United Handicapped Federation are logical extentions of the movement's emphasis on dignity and self-determination. These organizations, and similar ones emerging throughout the country, offer such services as peer counseling, assertiveness training, hot lines, and information and referral. Their members also tend to take an active interest in civic and legislative matters. These, then, are the

self-advocates; bringing their case directly to politicians and the press, and refusing to rely exclusively on those specialists and providers who, traditionally, have served as surrogate spokesmen.

Thus, what we are seeing is a shift in relationships within the human service constituency. The constituency consists of people who have a stake in the status of disabled citizens which encompasses more than one issue and which has lasted or can be expected to last several years. It includes disabled persons, their families, volunteers who've shown a long-term interest in disability issues, and people whose careers are tied to the rehabilitation field. Traditionally, the advocates for disabled Americans have been professionals who, in turn, received moral and financial support from parent activists. Often it was the parents who initiated partnerships with the professional community. Regardless how they were recruited, it has been the professionals who have drawn the plans and priorities; and, though parent and consumer power has often been responsible for getting appropriations through Congress, it has been the service providers who have sat down with Federal bureaucrats to decide how best to allocate the funds.

As the pressure from the self-advocacy movement has increased, however, some attitudes have changed and so have some rules. We can see the advocate's impact of the Federal-State Vocational Rehabilitation program, for example. For years, consumers have told Congress that VR agencies should be more responsive to consumer views. The success on Berkeley's Center for Independent Living and similar projects helped buttress arguments for expanding the decision making process. As a result, State VR agencies must now design and implement plans for consumer involvement.[6] The developmental disabilities concept is based on similar consumer involvements.

This mandate is yielding mixed results. In some states, the relationship between consumers and state agencies have not been at all cordial. Thus, the partnership envisioned by this mandate has had a slow start. In other states, however, we find agencies funding self-help centers and peer counseling, and find consumer advisory groups working with professionals to design pilot projects, rewrite client complaint procedures, and present budget requests to the legislature.

New Perspectives

The papers in this DDTAS series[7] attempt to examine the relation between perspectives towards disabled persons and the mission of rehabilitative planning in order to offer guidance to those involved in awareness campaigns. With self-advocates gaining the attention of politicians, the courts, and the press, the task of influencing public attitudes becomes rather complex; simply because the traditionalists and the new activists are presenting different views of reality. We do not have sufficient evidence to gauge the impact these conflicing messages have on the public. Within the human service constituency, however we see that as the power centers shift, expand, and contract, people are getting on each others' nerves.

This tension will affect not only those responsible for public information, but everyone in disability related work. What can public relations specialists and awareness advocates do? First, we must realize that guidelines, though important, have limits. Responding to issues, which can be done by circulating "thou shall not" lists, isn't enough. We must address the mission, which is both constant and ever growing. The process, the expanding constituency itself, is the problem; and unless individuals respond to that change they are not responding at all. Just as disabled people must be

allowed to participate in policy making and service delivery, they must also become partners in public advocacy. The point is not that you can buy off millitants by putting one of them on a campaign committee. The point is that unless we can treat each other as equals we don't know what we're talking about.

Today's consumers tend to have a small voice within the human service field. Planning is still done for disabled citizens, not with them. Yet things are changing. If the number of assertive consumers within the constituency continues to expand, if consumers continue improving their media and organizing skills, if self-help projects continue to multiply, and if disabled individuals become more visible members of society, there will be a wearing away of traditional resistance, and professionals, increasingly, will sense that it is time to consider new perspectives.

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Chapter 5

Hey, What's It Like to be Handicapped?
Practical Ideas for Regular Class Teachers and Their Students

Barbara Aiello

Eight year old Melody has just met her new neighbor, Mark, an eleven year old boy who has cerebral palsy. Melody is fascinated with Mark's wheelchair and interested in his unusual way of speaking, and like all kids, she's full of questions:

Melody: (Looking over the wheelchair) Hey, you sick or something?

Mark: No. I got cerebral palsy.

Melody: What?

Mark: Cerebral palsy. CP.

Melody: Oh, I get it. CP. (she pauses) Hey, What's CP???

Mark: It's something you're born with. It means you can't walk or talk so good.

Melody: You don't ever walk??!!???

Mark: No, but I get around real good in my wheelchair -- I call it my cruiser.

Melody: But how do you play, or go to school, or have any fun?

Mark: I go to school in a bus just like you do. But my bus is different. It has this real neal lift that picks me and my chair right up and puts us in the bus. And I play all kinds of things. You know, cribbage and monopoly, I do puzzles and I love to play checkers. . .

Melody: Checkers!! CHECKERS!! I just love to play checkers. Come on! Let's go on up to my apartment and we can play . . . Oh, I mean, well . . . . . uhhhhhhhhh . . . . . .

Mark: What's wrong?

Melody: Well, I mean . . . Well. Hey, can I catch CP??? I mean my Mom's gonna get real mad if I come down with what you got.

Mark: No, Melody, you can't catch CP. It's something you're born with. It's all right if we play checkers together.

* * *

Mark and Melody are not real children. Instead they are large, muppet-like puppets designed for use with regular class children to demonstrate what it's like to be handicapped and to illustrate the nature of positive peer relationships between disabled and non-disabled children.

When handicapped children enter classrooms with normal children, the disabled child often feels tense and conspicuous, while the non-disabled majority are often anxious about how to treat a child in a wheelchair, or a blind, deaf, or retarded classmate.

With the trend toward "mainstreaming" of handicapped children well established, such problems are on the rise and educators have begun to recognize the need for the careful orchestrating of the quality of life in classrooms where handicapped children are included with their nonhandicapped peers.

"Just because we have this new law (P.L. 94-142)," says one regular class teacher, "normal children didn't become more tolerant, loving, and understanding overnight." And for this reason a number of curriculum approaches have been developed which involve children in simulated experiences with handicapping conditions, encounters with the aids and appliances which handicapped people use, and discussions with handicapped people themselves. In addition, children and their teachers learn new ways to approach relationships with

handicapped children and adults through experiences with a variety of puppets which depict both handicapped and normal children.

Simulation Activities for Teachers

As part of a graduate course, "Mainstreaming: Translating Federal Law Into Classroom Practice," which I teach in conjunction with the Learning Institute, regular class teachers directly experience an intensive set of simulated activities designed to acquaint them with handicapping conditions and to develop these experiences into teaching tools to use with their own

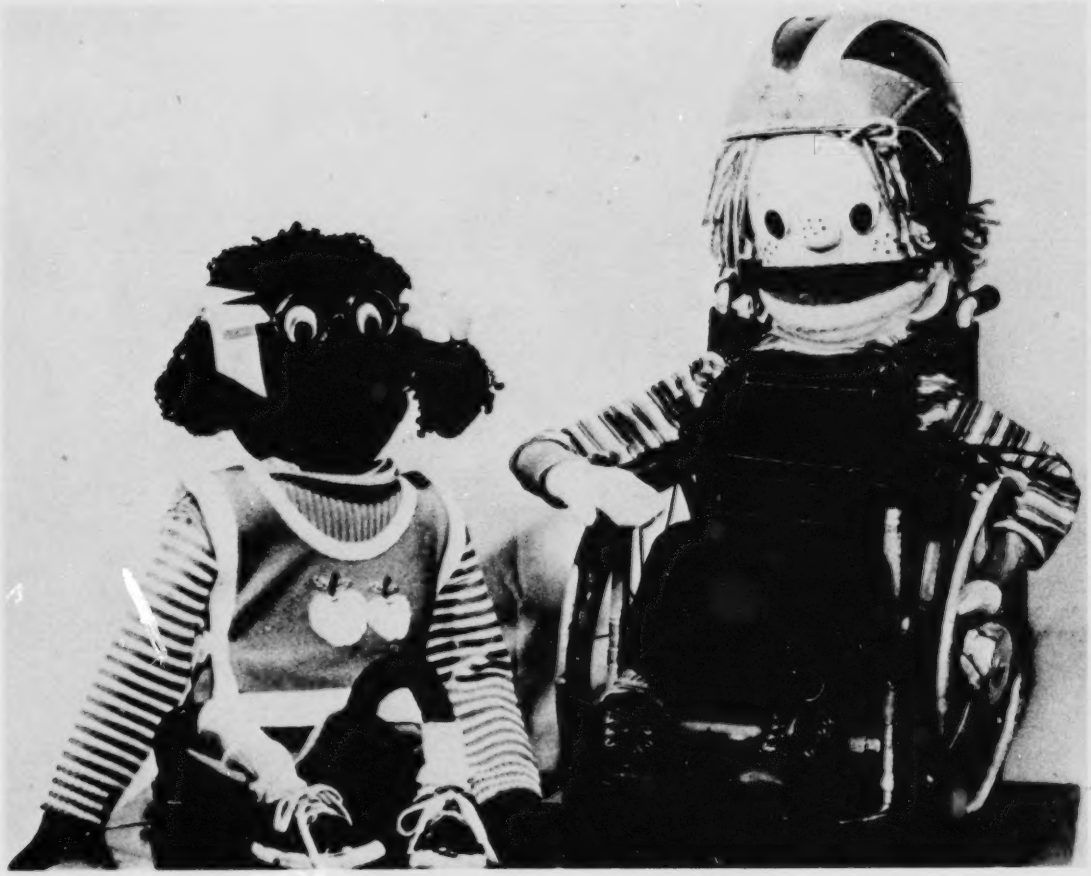

Photo: Barr A. Forrest

Can I catch CP??? I mean my mom's gonna be real mad if I come down with what you got!!!

children in the regular class.

When children are asked to tell about a handicapped person, most will describe a person who is blind. For this reason teachers first experience blindness as a handicapping condition. Divided into pairs, one teacher wears a mask (the half-face Halloween variety with the eye holes covered with mystic tape) while the partner leads her or him through a predetermined routine. Pairs are asked to help the blind partner put on a coat, walk around the classroom, walk outside, stop at the fountain for a drink of water, return the coat to the rack, and return to her/his seat. The non-blinded partners are encouraged to provide the assistance they feel is necessary, without leaving the blind person alone at any time.

After both partners have had a chance to wear the mask and be aided in following the routine, groups of four respond to the following questions: (a) How did you feel as the blind person? (b) How did you feel as the helper? (c) As the blind person, what sort of help did you receive? (d) As the helper what sort of help did you give? and (e) If you were blind first, did this experience influence the nature of the help you gave to your partner?

Unlike the "trust walks" popular during the humanistic education era of the early seventies, this simulation demands that participants examine not only the experience of being blind, but the nature of the helping relationship and the feelings of the nonhandicapped persons toward the handicapped partner.

When discussing cerebral palsy and related motor disorders, teachers again working in pairs, simulate the handicap. This time one teacher covers her/his hands with two pairs of thick socks and attempts to button and unbutton a shirt. Partners observe their efforts and then participate in the

activity themselves. Later small groups discuss their feelings of embarrassment and frustration, and their reactions to the laughter of their peers as each person attempted to do their very best at a very difficult task.

In conjunction with the motor simulation, teachers are taught to simulate impaired speech, a characteristic of many cerebral palsied and other neurologically impaired children. Each teacher is asked to jot down four to six lines of a familiar poem, song, prayer, or speech that she/he has committed to memory. In groups of four, teachers attempt to "speak their piece" while keeping the tongue locked behind the bottom teeth and not moving the lips. Each participant must make her/himself understood while the remaining three members of the group try to decipher what is being said.

Following this experience, teachers discuss whether it was more difficult to be the speaker or the listener, whether they made eye contact with their speakers, and how it felt to be misunderstood by a group of one's peers.

Planning Activities Aimed at Students

After teachers have experienced these simulations themselves, they are encouraged to adapt these and other activities to suit the groups of children they teach. For example, to simulate retardation, teachers are encouraged to repeat a long list of directions to their students. They might say, "Stand up, turn around three times, pat your head, hop twice, sit down again, stand up and stretch your arms, bow, touch your shoe, face the window." Students attempt to follow this sequence after listening to the directions only one time. When children have difficulty with the task -- "you went too fast," or "Slow down and repeat them slowly," -- teachers share with students that these feelings are like those felt by many retarded children. Teachers tell students

that "retarded means a little slow to learn and that when a child says to his retarded friend, 'Go inside, get your puzzle book and tell your mom you're coming over to my house,' the retarded friend may not be able to do all of those things, just as you normal children couldn't follow all of my directions." The teacher then discusses with the group practical ways to relate to retarded children.

And following each simulation activity, teachers continue the experience by providing students with the aids and appliances used by handicapped people whose conditions they have experienced via each simulation. A call to a local association for the blind often yields the loan of white canes, braille books, braille writers, braille card and board games, and even a typewriter. These materials can be placed in an interest center in the classroom where children can explore their use, discuss each aid, and contribute drawings and stories, as well as newspaper clippings to a bulletin board devoted to a particular handicapping condition. Rental agencies, hospitals, and special schools often will lend teachers wheelchairs, walkers, and therapy equipment, and children are encouraged to experiment with these devices as they broaden their understanding of a particular handicapping condition.

After the children have experienced the simulated activities and explored the aids and appliances used by handicapped people, they are ready to relate, on a knowledgeable level, to a person who is handicapped. Susan Robin Bookbinder, who developed a similar curriculum used in the Providence, Rhode Island schools, reports that children first ask questions which imply "How are we different?" and then ask questions which relate to "How are we alike?" When a blind woman visited her class, Bookbinder tells that the children held a lively debate about whether their visitor could cook. The blind woman permitted each child to share an opinion, pro or con, then explained how her

friends put braille labels on her canned and frozen foods and staple items so that she could fix all of her favorite foods, even spaghetti! When she told about how she planned to marry and have children, one seven year old girl responded, "What a relief. I thought handicapped people cried all day!"

Bookbinder cautions teachers to follow the curriculum process in sequence: (1) children experience the simulated handicapping condition, (2) children explore the aids and appliances used by a person with the handicap, and (3) children relate to a handicapped visitor. She emphasizes that children are far more amenable to talking with, rather than gawking at, a handicapped person when they have learned firsthand about the nature of the handicapping condition and have developed a respect for the skills the handicapped individual has learned in order to function in society.

Puppetry: A Special Activity

Puppets, like Mark and Melody who were mentioned at the opening of this chapter, are vehicles for permitting children to express their thoughts and concerns about what it's like to be handicapped. This and other vignettes which illustrate Mark's and Melody's developing friendship were designed around the questions children often have about handicapped people but are too afraid or too embarrassed to ask.

When Melody first meets Mark she is fascinated with his life in a wheelchair. She asks how he gets dressed, how he eats, and how he gets into bed at night, and after a sheepish pause, she asks, in a whisper, "How do you go to the bathroom?"

Mark explains that his brother and sister help him with his clothes, and that he uses a battery operated spoon to eat (I'll show it to you sometime,

Melody, it's real neat!"), and that the bathroom in his apartment has hand-rails beside the toilet so that he can wheel in and lift himself onto the toilet and go to the bathroom. "Neato," replies Melody. "I was really worried about that one. All my brothers go standing up."

In subsequent stories, Melody is reluctant to tell Mark that she is attending a play day at a local park on the same day that he has therapy. Melody feels guilty about going without him. Marks suggests that Melody have a good time and make some pictures for him about what she did at the play day. "I can't always do all the things you do," adds Mark. In this way, Mark shows Melody that being a friend doesn't mean sacrificing your own interests or dedicating your life to the handicapped person.

On another occasion, Mark accuses Melody of not returning a game, when she had in fact given the game to Mark's brother, who misplaced it. Mark doesn't give Melody a chance to explain and Melody becomes angry and finally cries. Mark's apology shows the children in the audience that handicapped people are sometimes short-tempered, and sometimes jump to conclusions, just as we all do. Many children believe that handicapped people are bastions of control who never lose their tempers or make a mistake. When Melody gets angry at Mark, she shows the children that treating a handicapped child with respect means behaving normally around her or him. Melody's behavior says to the children, "It's OK to be yourself, even if your friend happens to be handicapped."

In a sequence titled "Bionic Legs," Melody is bursting to tell Mark that she has found the solution to all of his problems. She knows how to fix it so that he'll walk, run, and even play kickball with her. She describes an episode on The Bionic Woman where the heroine has major repairs made on her

legs so that she will be able to walk again. Melody explains to Mark, "All you have to do is get your dad to take you to California where they make the bionic legs, see the Bionic Woman and she'll fix you right up, in time for baseball season!!"

Mark explains to Melody that The Bionic Woman is just a story, "a really neat story to get you to watch TV." When Melody is disappointed and depressed, Mark suggests a game of checkers. Melody agrees but mumbles, "I wish there was something we could do about your legs."

Mark's "older and wiser" comments to Melody show children that it is often the non-disabled person who has difficulty dealing with the handicapping condition. Mark has adjusted to his life in a wheelchair. Melody is learning to adjust to Mark the way he is.

Each sequence with the handicapped and normal puppets attempts to bring to light and to answer the questions hidden inside many non-disabled children, but Mark and Melody show children that tolerance and acceptance of handicapped people is not enough. We must learn to appreciate the difference that each handicapped person brings to our lives.

Closing

The puppets and the simulation activities are avenues for exploring, first the nature of difference, then the nature of appreciation of one person for another. As a classroom teacher said, "The law didn't make children more loving and understanding." She's right, but preparation, in the form of well designed activities that relate to the realities faced by handicapped children and their nonhandicapped peers is an important first step toward change -- the essence of the mainstream process.

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Chapter 6

Awareness Training for Police

Joseph A. Panza, Jr.

The Need for Awareness Training

Awareness training for police officers is long overdue. With more and more developmentally disabled people remaining in or returning to their communities, the police are becoming a vital resource for the protection of DD persons' rights, property, and liberty. But like other service providers, police need to know about persons with developmental disabilities in order to respond appropriately.

The goal of police awareness training is attitude change. To effect this change, a series of misconceptions must be confronted, challenged, and altered by information and experience. The police training workshops are the vehicles for facilitating this change in attitude. The workshops attempt to educate police personnel, both in-service groups and trainees, to recognize the developmentally disabled and to handle these people with proper police technique so as to prevent avoidable and inappropriate arrests.

Developing the Curriculum

Credit for developing the concept of police awareness training for the handicapped must be given to Mrs. Dolores Norley, the parent of a retarded son, and Special Advisor to the President's Committee on Mental Retardation. She developed the workshops with the cooperation of the national police chiefs' association and wrote the curriculum which is the cornerstone of the workshops. Copies of the curriculum guide are available form the National Association for Retarded Citizens. Follow the guide. It does a good job for a two hour session and is flexible enough to allow modification for longer sessions. It will save you many hours of preparation and can be used to incorporate other disability groups without any loss of focus. What modifications I've made represent a compilation of ideas that grew out of conducting workshops, feeling the need for improvement from feedback that more was desired, and a sense that more sensitization to the needs of disabled persons was necessary.

Designing the Training Sessions

Using the NARC curriculum, you can design your programs to meet a minimal two hour slot, or up to five or six hours. The problem I have found with the shorter sessions was that police wanted more and were frustrated when the presentation ended. The longer workshops provided more opportunity for imaginative presentations, more questions and answers, and group interaction, and greater rewards. But the longer format also puts a heavy demand on the presenter. Unfortunately, time is often a real problem over which you have no control.

In approaching police officers in a training group, it is imperative to remember police are trained to be protective of themselves and are likely to look askance at any training which leads them from that training or tries to

make them less suspicious. Getting their attention is easier when you appeal to their existing frame of reference and recognize that they are trained observers of behavior. What you are trying to do is refine their already proficient talent.

One advantage to police training is the imposed discipline. Everyone must report for training. It's an order. Police audiences are generally interested, pay attention, and enjoy an opportunity to learn. Sometimes the audience is armed so be careful not to arouse their ire! Seriously, you will seldom have attendance problems, troublemakers, or hecklers. Police are really interesting people. I've met police who were former teachers of retarded children, working on masters' degrees in police service, attending law school, were parents of handicapped children, etc. Therefore, be careful of stereotyping police. Do some homework. You'll find that police personality profiles parellel closely those of social workers in their desire to want to help others. Also, you'll find they try to be more dominant and authoritarian when they do help. A recent article by Lefkowitz (1977) in the American Psychologist is a good article for getting some feel for police organizational behavior and aspirations. How well you accomplish your task will depend upon your ability to understand police, communicate on their wavelength, and convince them you are on their side. So, do not antagonize or threaten them by being too smooth, "highfalutin," or acting like a "know-it-all." Give it to them straight and be honest.

The NARC curriculum guide will tell you to begin with everyone present before you conduct any of the training. After brief introductions, tell the audience your purpose and make a joke about giving out the final exam before the course. (See Supplement One.) Reassure them that the test will not be

graded, that only they will know their scores, and that they need not put their names on papers. As soon as everyone has finished go into the presentations.

At all times remember you're trying to get at misconceptions about the disabled. The questionnaire contains questions aimed at bringing these to the fore. Be prepared to explain answers, and to meet with dissent and disagreement. Handle these quickly and then move on. Many police are already sensitive to disabled people but perhaps out of sympathy rather than empathic understanding. Empathy is better particularly when based on understanding and experience. If you accomplish the abstract understanding from the questionnaire and the question and answer interchange, that's good. But it's not enough.

Using Videotapes for Training

Bringing disabled people to participate in the training is suggested by Mrs. Norley. Often, however, it presents logistical problems and may not be feasible. Recognizing this problem I have developed videotaped segments to draw the police as close to real life experiences as I could. To assist police in handling developmentally disabled persons, I use one tape to analogize an interrogation situation. Using both retarded and nonretarded persons I ask police to identify, visually at first, and then audiovisually those persons who are retarded. Normally there is confusion. This is good, because it generates clarifying questions and points out the difficulty in identifying the handicapped person by some gimmick or easy formula. The second tape grew out of the trainees often expressed desire to know how the developmentally disabled behave and what police could "typically" expect. For this, I developed a twenty minute group rap session of questions and answers among persons with

developmental disabilities. The topics range from independence, to marriage, work, voting, and to what it means to be handicapped. This tape offers real evidence that the developmentally disabled have opinions, can discuss everyday matters, and seem to be "just like other people" in so many ways when given the opportunity.

The videotapes provide the police with experiences to gain an empathic understanding from as close to real contact as one can feasibly bring them. Tapes are a second best alternative to live contact, but they are an effective way to accomplish the task of presenting disabled people as people first. Additionally, these tapes have been viewed by professionals, college students, and police groups alike. The net effect is usually the same: an open mouthed, incredulous look. Few people expect the retarded adult to have anything worthwhile to say, especially to express a personal opinion. Even we, human service professionals, can use a shot of empathic understanding now and then.

Finding a Training Sponsor

One ultimate objective should be the inclusion of an awareness training component relating to the developmentally disabled in every police academy at the state, county, and local level. That is to say, every policeman/woman should participate in this training either as a new recruit or as part of in-service training either at the police academies or through college courses. It is preferable that the training be included in the academy curriculum which provides broader scope and coverage. But this may be more difficult as training schedules are often tight and rigidly adhered to.

Like all new training concepts, you may have to sell the idea to key decision makers. While you may experience resistence to this notion, I have not. On the contrary, I have found police authorities eager to provide their people

with more learning opportunities. Your experiences can help you decide on the best approach to use.

Using your police training commission (or similar governmental body) can aid you in promulgating continuous training within your state system. Having instructors certified by the training commission, if you have one, makes your task easier and gives your training credibility and permanence which is desirable and tends to perpetuate the presence of DD representatives in the training sequences. By making contacts with a few key police personnel and criminal justice planners, you can spread the program ever wider. From there it is easy to envision how quickly one can involve judges, attorneys, probation and parole officers, and even legislators into the training process. There may be some opportunity to attract funding through SLEPA (State Law Enforement Planning Agency), for example, to do training of many kinds.

A Final Word

Police awareness training is important to the developmentally disabled population as they gain the status of full fledged citizenship with their full share of rights and responsibilities. Unless society understands and tolerates the sameness among people within the framework of peoples' differences, the group home movement, protection and advocacy rights movements, Section 504, and P.L. 94-142 will make no lasting difference to the disabled.

Police awareness training is, however, only one small step in the right direction. It is challenging, fun, interesting, and demanding. Starting the training requires large expenditures of time and energy, so it should be entered into only if a commitment is strong and the need clearly established. It is conceivable that a part-time effort could be employed depending on the scale of your enterprise and volunteers could be useful. Developmentally

disabled persons themselves may be able to offer a reality factor that no professional, who is not disabled, can. Keep in mind, too, that the program is easily modified so that community groups, neighborhoods slated for group homes and the other audiences can be exposed to the same basic format.

REFERENCES

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SUPPLEMENT ONE

1. What percentage of the population is retarded?

   a. 3% b. 5.4% c. 8% d. 10% e. 12%

2. The percentage of retarded people living in institutions is about:

   a. 3% b. 7.5% c. 10% d. 15% e. 25%

3. Retarded people:

   a. aren't very sensitive about their human dignity
   b. have the same needs you have have
   c. don't need as much self-fulfillment
   d. have a lessened need for love and loving
   e. aren't very aware of a feeling of self-worth

4. Authorities in the field of retardation approve most of a living situation where retarded citizens live in:

   a. rural areas b. villages designed for them c. institutions
   d. average sized residence in normal neighborhoods, rural or urban
   e. dormitories attached to workshops, for the period of training

5. Select the best of the following: most retarded adults

   a. can work on simple repetive jobs b. cannot work
   c. can work in sheltered environments d. can be kept busy in activity centers
   e. can work on competitive jobs in the community

6. The trend is to have retarded citizens be:

   a. more segregated from society
   b. given more separated services
   c. included in the full stream of society
   d. separated from society except in transportation
   e. separated from society only in employment.

7. If you're going to be retarded, you are

   a. born retarded
   b. retarded by early childhood
   c. a candidate for retardation at any age
   d. retarded before puberty

8. Heredity accounts for which percentage of retardation?

   a. less than 1% b. 7% c. 13% d. 20% e. more than 50%

9. Most retardation occurs because of:

a. lack of education b. inbreeding c. poor protoplasm
d. evil deeds e. unknown causes

10. Known causes of retardation are most connected to:

a. education b. wealth c. class in society d. race
e. pre-natal factors

11. Tomorrow any of us could be functioning like a retarded person, which of the following led to such a condition?

a. having a head injury b. using LSD c. having a heart attack
d. all of the above e. none of the above

12. Most retarded people are:
a. mildly retarded b. hopeless cases c. occasionally retarded
d. moderately retarded e. profoundly retarded

13. Most retarded people:

a. have speech problems b. have a dull look c. are normal looking
d. have abnormal gaits e. have epileptic seizures

14. Most retarded people:

a. live longer than most people because they have few pressures
b. live about as long as anyone else
c. die in early childhood
d. die in their first decade
e. die in their teens

15. Retarded people tend to be:

a. easily led into trouble b. resistant to persuasion
c. unpleasant to people in authority d. law breakers by nature
e. aware of future consequences

16. Retardation responds best to:

a. medicine b. psychiatry c. special education
d. physical education & treatments e. glandular treatments

17. Do you feel that retardation and mental illness are:

a. very similar to each other b. usually found in the same person
c. the same thing d. totally different problems
e. conditions which follow each other

18. Most retarded people:

a. are shy and backward
b. won't speak to strangers
c. don't like strangers
d. are suspicious of strangers
e. speak easily to strangers

19. Given the same situation, retarded people are more likely to be:

a. much more violent than the general population
b. much less violent than the general population
c. about the same as the general population in violence
d. slightly more violent than the general population
e. slightly less violent than the general population

20. Your best approach to get the most accurate responses from a retarded person encountered on the street is:

a. firm and authoritative
b. stern yet impersonal
c. official
d. friendly and calm
e. cool and detached.

Chapter 7

Institutions. . .
What Do We Do in the Meantime?

Daniel J. O'Connell

Background and Overview

The image of institutions for persons with developmental disabilities is at an all time low! Media exposés, class action suits, court decisions, and widespread mistrust contribute to a rapidly escalating negative attitude shared by the general public. This perception is reflected by a defeatist attitude among staff, regular condemnations by consumer groups and the frequently biased manner in which media representatives approach, or fail to approach, the sensitive topic of life in institutional settings.

What was thought to be a solution to a problem twenty years ago is now perceived by many people as an extension of the very problem which it was intended to solve. Mass congregate living for the developmentally disabled is being condemned with a degree of certainty and swiftness never before seen in this field. Unfortunately, most things associated with institutional life are also being condemned as well.

The result of such a rapid swing of the pendulum is both predictable and

obvious: defensiveness, devisiveness and immobilization. Morale of even the most dedicated staff is reduced to near zero as many administrators are forced to adopt a "steady as she goes" attitude awaiting the demise of recently developed programs and the demolition of buildings still under construction. With no one being able to predict the future with any degree of confidence, new initiatives are faced with ambivalence and long range planning for institutions is at a standstill. Surrounded by uncertainty, staff of institutions feel becalmed by the lull before the storm.

Will institutions ever be totally abolished: The reality of our situation is that the total elimination of institutional life for the developmentally disabled probably will never arrive. It certainly will change dramatically, and take on a new form and direction, but total elimination will never be fully achieved. Consequently, the transition from massive institutional settings to smaller community based living arrangements for the developmentally disabled must be seen as a process of evolution, not revolution as some might hope. Public sponsored group living arrangements for special citizens shall continue in one form or another as part of our system.

This statement is based upon a respect for the influences of pragmatism and moderation on the political and social processes which dictate the norms and parameters of human service programs. It certainly doesn't reflect professional idealism, but rather is intended to interject a keen sense of reality into our thinking. In short, little evidence can be found that society is ready to pay the price associated with the total elimination of institutions for persons with developmental disabilities.

If one accepts the premise that we're talking about the reduction of institutional settings and not elimination, fewer, better and smaller facilities

become a more reasonable expectation. Admittedly a far cry from the total elimination of all forms of congregate living, it must be remebered that even this more modest goal represents a significant departure from our position a mere decade or two ago. Then, we all remember, construction of very large "Village of Happiness" type of facilities was the only answer. Having finally convinced the public of the value of large, rural and (please excuse the word) "terminal" facilities, we are now drastically changing our message. There should be little reason to wonder why the general public appears confused.

The Need to Communicate

During difficult transitional times, the need for effective public awareness becomes critical! Of course, this process never stops, but change in program direction makes it even more essential. Radical departure from previously espoused tenets and theories can seriously undermine our public credibility unless accompanied by a sound public awareness process. Lack of indepth public awareness will create and perpetuate barriers to change. This is our position today.

Responsibility for ongoing public awareness processes is shared by many individuals but at this moment in our development there is a crucial role which must be undertaken by the administration and staff of institutions for persons with developmental disabilities. It is critical that the various public audiences hear the voice of the institution addressing such sensitive and complex issues as deinstitutionalization, community based living arrangements and normalization. Unfortunately, silence will be interpreted as lack of support and used to reinforce resistance.

Staff of institutions are being challenged to be leaders of a process which had radical personal and professional implications. This is not a

pleasant undertaking. Not only do staff members have a vested interest in institutions as they are currently functioning, but all of us find it very difficult to be perfectly candid and objective about something which we helped create. Job security, professional esteem and the need to accomplish something worthwhile are factors which motivate nearly everyone. Historically, institution staff have been forced to assume a very defensive posture with regard to dealing with the various public groups. How, therefore, do you reverse this process and begin a well planned, progressive and objectively candid public awareness effort to address the real issues affecting lives in institutional settings? It's not easy! But there are some guidelines.

Start at the Top

As with most major undertakings, support from top leadership insures greater chances of success. Program leaders have to recognize the need for increased public awareness efforts and establish a policy whereby staff at all levels of administration are expected to participate in these activities.

This does not imply that agency directors should determine the message to be given, and then pass it on to staff to be delivered. Such a practice would obviously be stifling and unfair to both staff and clients. Messages will vary, as well they should, because we are dealing with complex issues for which there are no simple universal solutions. The agency administration, however, has to be secure and confident in encouraging processes of open communication with various publics to develop at all levels within an agency.

This is an area in which State Developmental Disabilities Councils have much to contribute. As a statewide planning force for persons with developmental disabilities, state councils should be providing leadership, technical assistance and funds to state programs ready to undertake public awareness

activities. State councils are also capable of supplementing agency efforts, and should readily do so. These efforts would be invaluable.

You Are Important

You, the staff of institutions, are important for the success of public awareness activities for two basic reasons. First, the job is a vast complex process which demands input from many persons at many levels. Second, no one knows what you know and your personal knowledge is indispensable.

This is not a one person job, nor is it a project or task which will some day be completed. Wish as we might, the job will never be finished. Instead, we are talking about an ongoing process of sharing a great deal of information with many different public audiences at the same time. Such divergent groups as the power structure, community groups, consumer representatives and the general public have very individualistic information needs. There is no single slogan or jingle which will suffice, and no single person or group which can do justice to this task. We are all important.

Yet the most important person is you. You have your own story to be told, your own perception of the problem and your own cultivated, ready-made audiences to listen. Your audiences, regardless of whom they are, count and no one can be more effective in communicating with them than you. Be open, honest and candid. Tell your story!

Let the Institution Speak for Itself

Institutions have a unique ability to tell more about themselves than we sometimes give them credit for. Let them do it!

Various public audiences should be regularly and systematically invited to visit institutions, and allowed to draw their own conclusions. Although most facilities claim to operate an "Open Door" policy, some doors at many

institutions are never opened. Understandably reluctant to expose our shortcomings, failure to open doors will perpetuate that which we are most committed to eliminate.

Although maintaining openness and total candor is important, great care must be taken to be certain that residents are not embarrassed or exploited in the process. Obviously the need for personal privacy, dignity and respect must prevail in these activities.

Focus on People Not Buildings

The importance and meaning of institutions is not the buildings, but the people in them. Too often we forget that. In our zeal to point out decay and deterioration, we focus our attention and that of others on physical structures and not on physical beings. As long as we continue this practice, our results will be minimized.

It is the plight of people we need to address; the needs, wants, abilities and feelings of large groups of people living in surroundings which frequently neither you nor I could tolerate. This is our message and it must be shared with many diverse audiences. We're really talking about common human needs.

Not all news relies upon sensationalism. The general public still listens intently and compassionately to human interest stories. Within the wall of any institution exists countless messages about people which have relevance and meaning to today's debate regarding the future of large facilities. A story about an elderly person who has spent his entire life on the grounds of one facility or the message about the reaction of a child recently admitted can convey many critically important and complex messages very effectively.

Summary

Institutions for persons with developmental disabilities are under attack and their role is changing. In this transition, there is a clear and compelling need for administrators and staff of institutions to speak out about their own fate. Failure to do so will be interpreted as lack of support for change which is inevitable and essential.